Questionnaire-Based Measurement for Surveys and Other Data Systems

Version 4.00

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#### I. Introduction

There is a continued need for high-quality, questionnaire-based data to develop and evaluate HIV, STD, and TB prevention/elimination programs. Self-reported behavioral data can compliment incidence and prevalence surveillance data in monitoring and anticipating the course of an epidemic. Questionnaire-based data related to HIV/STD and TB prevention is collected in a number of settings including general population surveys, behavioral surveillance systems of high-risk and infected populations, and as part of intervention studies. However, the necessary integration of data derived from these systems is often hampered by a lack of comparability between data items intended to measure the same behavior or concept.

The HIV-STD Behavioral Surveillance Working Group was formed in the fall of 1997 to address the need for comparable data across various data systems by developing and promoting the use of common questionnaire items related to HIV/STD/TB risk and prevention. The HIV-STD BSWG seeks to coordinate and enhance existing data systems and methods, in order to provide data for use of planning and evaluating prevention programs at the national, state, and local levels. The core items offered here on drug-related HIV risk and preventive behavior, as well as the Sexual Behavior and HIV Testing core items, are the principal results of this effort.

The text proceeding the core items provide a synopsis of the purpose, scope, and current development status of the core items for drug-related HIV risk and preventive behavior. Interested readers are referred to Introduction to the Core Questions for a more detailed explanation of the rationale and methods used by the working group to produce the core items.

### II. Purpose and Scope

Prevention planners and policy makers working at the national, state, and local level require timely, relevant, and representative HIV risk and preventive indicator data to develop rational and effective prevention programs and policies. There is wide consensus that the lack of

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coordination across questionnaire-based data collection systems for these indicators precludes these systems from providing the information required. The core question items were developed to address one aspect of the coordination effort; that of improving the comparability of data items that are intended to measure the same behavior or concept across systems. The purpose of the core question items then, is to promote standardization of key items across disparate data systems so that minimal data needs of prevention planners and policies makers can be addressed.

Behavioral (and other) indicators are currently collected at the general population, infected population, and high-risk population levels. General population surveys typically have strong sampling methodology and provide results that are generalizable to the total population. They can measure the impact of prevention programs on the general population, and can provide a baseline with which to compare high risk samples. However, they provide limited information on relatively rare risk behaviors, particularly among high-risk subgroups such as men who have sex with men and injection drug users. Surveillance of infected populations yields information on risk for infection acquisition and ongoing transmission, but do not provide information on at-risk, yet uninfected populations. Surveillance among high-risk populations fills this void, but is often dependent on convenience sampling, and therefore limits the degree to which the results can be generalized. The necessary integration of data derived from these systems is often hampered by a lack of comparability between data items intended to measure the same behavior or concept. Use of the core questions as a common standard would allow for integration, and thus vastly improve the quality and quantity of information produced.

The core question items are not intended to serve as a complete, "off the shelf" survey. Rather, they suggest: (1) a standard question and response format for items, and (2) only those items that are considered to address minimal data needs, or "core" items. The items offered here are considered the basic and necessary components to be included in questionnaire-based measures of drug-related HIV risk at the three population levels.

To allow for comparison across all three surveillance levels, but address only the minimal data needs for each, two "tiers" of questions were developed. The first tier questions are considered the minimal number of questions to be used in all surveys. These questions are suitable for general population surveys, and thus do not include questions of high-risk behaviors that are relatively rare among the general population. The second tier questions include the first tier, as well as additional questions that obtain more detailed information about high risk behaviors that are relevant to high-risk and infected populations. The additional items in the second tier are intended to address minimal data needs for high risk and infected populations.

The core question items are intended to be serviceable across a broad range of surveys with various objectives, target populations, and data collection settings, while maintaining a sound methodology and addressing the identified minimal data needs. Even so, it is recognized that the

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questions are not capable of serving the specific purpose of every researcher. First, because the core questions address only minimal data needs, they consequently exclude an array of important questions and topics of interest to researchers. Second, the core items were developed to suit interviewer administration, and may need to be adapted for use in other settings (e.g., self-administered). It is also likely that the formatting (e.g., question order), or question wording may not suit the particular situation (e.g., for a jail or prison setting). It is also possible that only certain items from the second tier are relevant for the study. Therefore, researchers are encouraged to add additional questions of interest, extract relevant portions when necessary, change the format, and otherwise adapt the core questions to suit the unique purpose of their study.

We hope that persons conducting studies will be able to adopt the questions we recommend. We realize that in some instances researchers may find it necessary to use a different form of a question, for example in order to maintain a continuous time series. In those cases we would urge the researchers to adopt both questions – this would have numerous advantages, allowing for internal as well as cross-study comparisons, and maintaining time series. The small number of basic core questions adds little additional cost, especially in light of the many benefits.

### III. Development and Status

The methodology employed by the working group to develop the core measures can be best described as a modified Delphi approach and is comprised of the following iterative steps: 1) identification of existing surveys, questions, and relevant behavioral elements; 2) creation of a survey database; 3) review of published data or analyses of existing available data; 4) discussion of draft core questions; 5) distribution of draft questions to internal and external consultants to obtain feedback; 6) cognitive testing; 7) inclusion of core questions in existing surveys to obtain pilot data; 8) redrafting of questions on the basis of pilot data and feedback; 9) dissemination and support of core questions; 10) ongoing evaluation, feed-back, and adaptation of questions.

All of the core measures are developed and continually revised by this iterative process. The drug core measures offered here have undergone intensive review by external consultants, and have been revised based on the feedback received. Further refinements of the questions will be made based on additional feedback, results of cognitive testing, and the results of pilot testing.

The working group identified and adopted the "critical event" concept to guide the development of all the core question items. Using the critical event approach, questions refer to the behavior of the respondent the last time the event occurred. The advantages of this approach include minimal recall bias and that it allows for simple categorical (yes/no) responses. The disadvantage of using critical events is the potential of losing detail on less likely events. There

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again, researchers are encouraged to use additional questions that obtain the data of interest.

The drug-related HIV risk and preventive behavior items address injection drug use, non-injection drug use, and crack use. The twelve first-tier questions produce estimates of life-time use ("ever") and 12-month use in the three categories. The first tier also includes items that address needle hygiene, needle source, and type of drug used at the last drug-use event.

The second tier questions include these items, as well as additional items that obtain detail on injection drug, non-injection drug, and crack use. In all three categories, past 30-day use and the number of days used in the past 30-days is included. More details on needle hygiene, such as sharing injection drug paraphernalia (cookers, cottons) and specifics about sharing at the last event, are obtained.

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#### First Tier Questions

### **Injection Drug Use**

EXAMPLE INSTRUCTIONS – The next set of questions are about using a needle to inject any drug. This would include drugs such as heroin, cocaine, amphetamines, or steroids, but does not include any drug taken under a doctor's orders.

1. Have you ever, even once, used a needle to inject any drug? DO NOT include anything you took under a doctor's orders.

Yes No (skip to 6)

2. In the past 12 months, have you used a needle to inject any drug?

Yes No (skip to 6)

3. The last time that you used a needle to inject a drug, what drug did you inject? (Check all that apply)

Heroin	Yes	No
Powder Cocaine	Yes	No
Crack Cocaine	Yes	No
Methamphetamine	Yes	No
Other (specify		

4. The last time you used a needle to inject a drug, was it a new, sterile needle? By sterile, we mean that it had never been used before, not even by you.

Yes

No

Don't Know

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5.	The last time you used a needle needle? Pharmacy Needle Exchange Street Shooting Gallery Other (specify		ct a drug, where did you get the
Non-	-Injection Drug Use		
snort	MPLE INSTRUCTIONS The next so ing any drug that was not taken under de times that a drug was taken by inje	r a doctor	's orders. This set of questions does not
6.	Not counting drugs that you in sniffed, snorted, or taken any dryes	•	ave you ever, even once, smoked, to get high?
7.		_	igs that you injected, have you ever, r taken any drug just to get high?
8.			he <u>last time</u> you used a drug that , what did you use? (Check all that
	Marijuana	Yes	No
	Powder Cocaine	Yes	No
	Heroin	Yes	No
	Methamphetamine	Yes	No
	Ecstacy	Yes	No
	Psychedelics (LSD, mushrooms)		No
	Inhalants	Yes	No

Yes (END) No

**Crack Cocaine** 

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	Other (specify)
9.	Have you ever, even once, smoked "crack" cocaine? Yes No
10.	In the past 12 months, have you smoked "crack" cocaine? Yes No
	*****END OF FIRST TIER QUESTIONS*****

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### **Second Tier Questions**

### **Injection Drug Use**

EXAMPLE INSTRUCTIONS – The next set of questions are about using a needle to inject any drug. This would include drugs such as heroin, cocaine, amphetamines, or steroids, but does not include any drug taken under a doctor's orders.

1.	Have you ever, even once, used a needle to injected any drug? DO NOT include anything you took under a doctor's orders.
	Yes No (skip to 18)
2.	In the past 12 months, have you used a needle to inject any drug?

3. In the past 30 days, have you used a needle to inject any drug? Yes

No (skip to 5)

Yes

No (skip to 18)

4. In the past 30 days, on how many days did you use a needle to inject any drug?
Number of days: \_\_\_\_

5. The last time that you used a needle to inject a drug, what drug did you inject? (Check all that apply)

Heroin	Yes	No
Powder Cocaine	Yes	No
Crack Cocaine	Yes	No
Methamphetamine	Yes	No

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	Other (specify)
6.	The last time you used a needle to inject any drug, was it a new, sterile needle? By sterile, we mean that it had never been used before, not even by you.  Yes (Skip to 8)  No Don't Know
7.	The last time you used a needle to inject a drug, did you use a needle that you knew or suspected someone else had used before? Yes No Don't Know
8.	The last time you used a needle to inject a drug, where did you get the needle? Pharmacy Needle Exchange Street Shooting Gallery Other (specify)
9.	The last time you used a needle to inject a drug, did you use cottons, a cooker, or rinse water that you knew or suspected someone else had used before? Yes No Don't Know
10.	The last time you used a needle to inject a drug, did someone else use the

needle after you?

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Yes	
No	
Don't	Know

11. The last time you used a needle to inject a drug, did someone else use the cottons, cooker or rinse water after you?

Yes No

Don't Know

12. The last time you used a needle to inject a drug, did someone use their syringe to squirt the drug into your syringe? This is sometimes called "backloading", "frontloading", or "splitting".

Yes

No

Don't Know

13. The last time you used a needle to inject a drug, did you use your syringe to squirt the drug into the syringe of someone else? This is sometimes called "frontloading", "backloading", or "splitting".

Yes

No

Don't Know

### Non-Injection Drug Use

EXAMPLE INSTRUCTIONS-- The next set of questions are about smoking, sniffing, or snorting any drug that was not taken under a doctor's orders. This set of questions does not include times that a drug was taken by injection with a needle.

14. Not counting drugs that you injected, have you ever, even once, smoked, sniffed, snorted, or taken any drug just to get high?
Yes

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15. In the past 12 months, not counting drugs that you injected, have you smoked, sniffed, snorted, or taken any drug just to get high?

Yes
No (END)

16. In the past 30 days, not counting drugs that you injected, have you smoked, sniffed, snorted, or taken any drug just to get high?

Yes
No (skip to 26)

17. In the past 30 days, not counting drugs that you injected, on how many days did you smoke, sniff, snort, or take any drug just to get high?

Number of days: \_\_\_\_\_

18. Not counting drugs that you injected, the <u>last time</u> you used a drug that you smoked, sniffed, snorted, or taken, what did you use? (Check all that apply)

Marijuana	Yes	No
Powder Cocaine	Yes	No
Heroin	Yes	No
Methamphetamine	Yes	No
Ecstacy	Yes	No
Psychedelics (LSD, mushrooms)	Yes	No
Inhalants	Yes	No
Crack Cocaine	Yes (Skip to ??)	No
Other (specify		)

19. Have you ever, even once, smoked "crack" cocaine?

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	Yes No (Skip to Q 22)
20.	In the past 12 months, have you smoked "crack" cocaine? Yes No (skip to Q 22)
21.	In the past 30 days, have you smoked "crack" cocaine? Yes No (skip to 22)
22.	In the past 30 days, on how many days did you smoke "crack" cocaine? Number of days:
23.	Not counting drugs that you injected, the last time you used a drug, how did you take the drug? Did you:  Sniff it  Smoke it (END)  Eat, drink, or chew it (END)  Or did you take it some other way (how?)(END)  Don't know
24.	When you sniffed or snorted the drug, did you put a straw or other object in your nose to inhale the drug? Yes No

\*\*\*\*\*END OF SECOND TIER QUESTIONS\*\*\*\*\*\*